White Paper on Evaluation of Sampling Design Options for the National Children's Study

Appendix G

White Paper on Recruitment and Retention for the NCS

March 2004

White Paper

On

Recruitment and Retention for the

National Children's Study

by

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GLOSSARY OF STUDY ABBREVIATIONS

Study Abbreviation	Full Name
NHEXAS Region 5	National Human Exposure Assessment Survey, EPA Region 5
NHEXAS Maryland	National Human Exposure Assessment Survey, Maryland
NHEXAS Arizona	National Human Exposure Assessment Survey, Arizona
NLSCY	National Longitudinal Survey of Children and Youth
DNBC	Danish National Birth Cohort
CPP	Collaborative Perinatal Project
Diana	Diana Project
ALSPAC	Avon Longitudinal Study of Parents and Children
BCS46	British Cohort Study, 1946 Cohort
BCS58	British Cohort Study, 1958 Cohort
BCS70	British Cohort Study, 1970 Cohort
Bogalusa	Bogalusa Newborn-Infant Cohort
Boston NO_2	The Boston Residential NO_2 Characterization Study
ECLS-K	Early Childhood Longitudinal Study: Kindergarten Class
FCS	Framingham Children's Study
NCICAS	National Cooperative Inner-City Asthma Study
NHANES I	National Health and Nutrition Examination Survey I
NHANES II	National Health and Nutrition Examination Survey II
NHANES III	National Health and Nutrition Examination Survey III
NHSDA	National Household Survey on Drug Abuse
NSAF	National Survey of America's Families
Tucson EPI	Tucson Epidemiologic Study
SIPP	Survey of Income and Program Participation
MUSP	Mater Misericordiae Mother's Hospital-University of Queensland Study of Pregnancy
FHS	Framingham Heart Study

White Paper

On

Recruitment and Retention in the National Children's Study

Ben Pierce, Pam Hartford
Battelle

G-1 INTRODUCTION

The purpose of this white paper is to provide the National Children's Study (NCS) Program Office at NICHD background and information on recruitment and retention methods and historical rates that may be useful to the formulation of design options for the NCS. This paper is based upon results of previous discussions regarding recruitment and retention for the NCS (11, 44). Additionally, a literature review was conducted to capture information from previous studies that were relevant to the NCS.

The literature search was accomplished by conducting a search across several bibliographic databases, including MEDLINE, Pascal, EMBASE, FEDRIP, ToxFile, SciSearch, Biosis Previews, TGG Health & Wellness, ELSEVIER BIOBASE, Cancerlit, Dissertation Abs Online, General Science Abstracts, Global Health, CAB Abstracts, SportDiscus, NTIS, JICST-EPlus, New England Journal of Medicine, FOODLINE, and Energy SciTec. This bibliographic database search included mainstream scientific and medical journals, including those focusing on pediatric health. Keywords used for the search included: longitudinal, review article, methodology(ies), design, prospective, cohort, infant, child(ren), natal, prenatal, perinatal, postnatal, and pregnancy. Years included in the search were limited to 1980 through the present. A similar search was conducted using the Current Index to Statistics, which contains listings of statistical and mathematical journal articles from most major statistical journals.

Using this search strategy, there were several hundred hits. Due to the extensive nature of the literature, and time and resource constraints, coverage of all possible relevant topics was impossible. For the purposes of this paper, we were interested in the initial response and retention rates, and the implications of these rates for the NCS design (e.g., limitations, target populations). Therefore, efforts were prioritized to focus on literature that was most relevant to three main questions: 1) How should subjects be recruited? 2) How are subjects retained over time? and 3) Does the article/study provide information on tracking/locating study participants? If an article addressed any of these questions (including study design and participation incentives), it was considered highly relevant. Additional criteria used for selecting relevant literature included whether the study focused on children, relevant health outcomes, and length of the study.

The reference sections of studies or articles identified as potentially relevant to providing insight into recruitment and retention for the NCS were examined for additional articles and

studies. These articles and studies were then obtained and reviewed for relevance. Due to resource constraints, an exhaustive review of all available literature was not conducted. However, many of the articles that were identified through the reference sections of relevant articles were obtained and reviewed.

Overall, it does not appear that there has been a single study that employed exactly the same scope, size, and design as that being considered for the NCS. Differences in the identified studies include: much smaller sample sizes, lower burden on respondent, absence of the collection of environmental samples, geographically smaller areas, etc. However, many of the studies and papers in the current literature do provide an opportunity for gaining insight into the potential methods for recruitment and retention in the NCS. This paper summarizes the salient issues with respect to recruitment and retention, as identified in the published literature, and suggests the implication to the NCS.

G-2 RESPONSE RATES

Many different definitions of response rates exist in the current literature. For example, some authors define the response rate as the number of completed interviews divided by the number of potential respondents in the population of interest, or in the selected sample (45). Others define the response rate as the number of completed interviews divided by the total number of eligible respondents (i.e., persons who have been recruited to participate in the study and meet the criteria for inclusion) in the sample. Many researchers report a variation of the Council of American Survey Research Organizations (CASRO) standard response rate, which is defined as the number of completed interviews divided by the number of units that were requested to participate and were eligible for the study (46). In some surveys, such as those conducted through telephone methods or multistage cluster samples, defining the number of eligible reporting units is not straightforward. For example, if contact with a potential respondent is never made via telephone or if some sampling units (or blocks) within a geographic cluster are not enumerated and screened, it is impossible to determine if there is an eligible respondent in the household. In these cases, it is often assumed that the eligibility among cases where eligibility could not be explicitly determined follows the same distribution as the eligibility among cases where the eligibility can be explicitly determined.

Response in the NCS is a significant factor that should be considered in the overall design. The initial response rate will establish the response rates for subsequent data collection stages because the response rate for a later stage in a longitudinal study is typically calculated as the initial response rate multiplied by the response rates for subsequent stages of the survey, unless additional participants are permitted to join the survey after the initial data collection effort. Although imperfect, response rates are viewed by many as a barometer for whether the survey will suffer from a sampling bias due to non-response. Certainly, it is possible to have a study with a low response rate and not have an issue with non-response bias, or be able to correct for non-response through weighting adjustments. It is equally possible to achieve a high response rate but still have a biased sample. However, generally speaking, higher response rates are desirable because they make easier the task of defending the study against criticisms of bias.

They also reduce the need for weighting adjustments and they add credence to the study results. In short, non-response generates uncertainty in the data that should be avoided if possible.

G-2.1 SOME KEY FACTORS THAT INFLUENCE RECRUITMENT RATES

There are a number of factors that have a significant influence on the recruitment rate for a study. It would be impossible to list or discuss every possible factor associated with achieving a particular response rate because these factors can range from characteristics of the interviewer to the time of day that the potential respondent was first contacted (1, 24, 32). However, there are a few key factors that should be considered as part of the design for the NCS. One key factor that has been shown to impact the response rate is the method of recruitment. Other factors that influence the response that should be considered in the design of the NCS include respondent burden or the perception of burden, use of incentives, and participant's motivation/knowledge. There are also considerations of the ease or limitations on participation (e.g., available appointment times, access/distance to facilities).

Method of Recruitment

The method by which participants are contacted and recruited into the study will have a significant impact on the recruitment rate. Booth and Johnson (47) have suggested that a probability approach using a telephone-based selection and recruitment method is a viable option for recruiting participants for a longitudinal survey. However, initial response rates for surveys conducted via telephone have been steadily declining over the past ten years due to increases in technology and the negative influence of marketing calls on the willingness of potential respondents to participate. Cox et al. (45) examine the response rates of 40 surveys conducted in the 1990s through telephone methods and report interview response rates ranging from 35 percent to 84 percent, with a median of 61 percent. Although many of these studies were cross-sectional in nature, the initial response rates for longitudinal studies could be expected to be similar, if not somewhat lower. Booth and Johnson (47) report an initial response rate of 65 percent and Brick et al. (48) report an initial response rate of 77 percent. However, in terms of a longitudinal survey, initial response rates of 60 percent to 70 percent may not be sufficient to ensure that the response rates at subsequent stages are adequate, even if the response rates for each particular wave of the survey are very high. For example, Booth and Johnson (47) report a follow-up response rate of 78 percent, which yields an overall response rate of 51 percent for the survey. Brick et al. (48) report similar results (80 percent response rate in follow-up survey, yielding a 62 percent overall response rate), which lead them to question the feasibility of employing a telephone recruitment method for longitudinal surveys. By contrast, initial response rates for personal interview surveys, where the initial contact is made in a face-to-face contact, are generally higher than those found in surveys that employ telephone recruitment methods (49).

Physicians are a point of contact for women and their young children. Routine checkups provide an opportunity for scheduled, in-person interaction between a physician and the mother/child. Moreover, physicians may be in a unique position to recruit women and their children into the study because of an established, trusted relationship. The use of physicians to recruit women for a study is a common practice for clinical trials and health outcomes research

and has been used for several surveys in the U.S. and abroad. One potential disadvantage of having physicians recruit participants is that unless a probabilistic sampling plan is used (e.g., a systematic plan to invite every n^{th} patient), there may be sampling bias introduced by the physician. For example, physicians may be more apt to recruit women/children who are less-healthy so that they can have the advantage of the medical care and treatment that the NCS would provide. Alternatively, some physicians may recruit healthier participants for other reasons. Initial response rates for physician-based surveys are difficult to calculate since many physician surveys essentially become a "volunteer" sample, whereby the physician informs potential participants of the study indiscriminately and does not work from a probability sampling structure. For example, in Denmark, 3,500 physicians were asked to invite women to participate in the Danish National Birth Cohort Study (7). The study researchers estimate that roughly 60 percent of all eligible women were invited to participate and that roughly 60 percent of those invited actually participated.

Another potential disadvantage in utilizing physicians to recruit women is that the physicians themselves will need to be approached and "recruited" for participation in the study. Incentives will likely be necessary to entice physicians to participate. However, there is the possibility that bias will be introduced in the sample if the patients of non-participating physicians are systematically different in some characteristic than patients of participating physicians. Another issue raised is whether the physician is the best person to represent the study, and recruit or convert reluctant participants.

A center-based approach has many of the same advantages and disadvantages that a physician recruitment method has. In short, the advantages are established relationships/ reputation with potential participants, opportunities for in-person interaction with participants, awareness of community issues and concerns, and a perception of trust from potential study participants. The disadvantages include the tendency towards a "volunteer" sample, or the introduction of sampling bias on the part of a physician or center coordinator. Obviously, these disadvantages can be lessened through the use of a strict sampling protocol.

Respondent Burden

Respondent burden has long been thought to have an inverse relationship with response rates. That is, increasing the burden on the respondent generally reduces participation and hence the response rates. Although there are many reasons why respondents may refuse to participate, one likely factor is the unwillingness by the respondent to give up personal time, which is perceived as precious (50). Therefore, the length of the various interviews, requirements for data collection outside of the home, collection of detailed diaries, and even the scheduling of the collection of environmental samples in the home require time from a respondent and therefore add to respondent burden. Another aspect of this is that there are likely to be limitations in the time(s) that are available to schedule visits, both for clinic and home visits (based on available staff and distances) that limit participation. Accommodating these limitations poses an addition burden on the participant; inability or unwillingness to accommodate could reduce participation rates for some measures. Additionally, the NCS will involve the collection of biological and environmental samples, which may make potential participants hesitant to participate because of the invasiveness of the sampling, real or perceived, or the potential risks of the procedures and data collection.

With a longitudinal survey, there are two components of burden: (1) the burden associated with completing the immediate task at hand, and (2) the perceived burden of future data collection activities/requirements (51). Both of these burdens can impact the response rate because respondents will consider the "costs" of future burden when deciding whether to participate in the initial data collection effort (52). Apodaca et al. (51) found that the perception of future burden resulted in a five percent decrease in the initial response rate.

With the NCS, there is the potential for significant burden for study participants, both in terms of the actual burden and in terms of the perceived burden. There are a number of different data collection stages, including the collection of environmental, biological, and questionnaire information. All of these different data collection activities will require some portion of the respondents' time and effort, and will therefore increase their burden. Additionally, it will be important to carefully manage the potential study participants' perception of burden at the initial recruitment stage because this perception also can have a negative impact on participation. The recruitment and data collection strategy may increase or decrease the actual or perceived burden. For example, a physician-based recruitment approach may not be perceived as additionally burdensome because many mothers already are taking their young children to physician offices for routine checkups.

Incentives

Incentives have been used in many different surveys as a mechanism for increasing participation. Although the impact of incentives can vary from survey to survey, even a small incentive can result in some improvements in response rates (53). A recent report titled "Development of Exposure Assessment Study Design for the National Children's Study" prepared by Strauss et al. (44) contains a detailed discussion on the use of incentives for survey research as it may relate to the NCS. The following summarizes the discussion contained in that report.

> *Recent studies demonstrate that incentives do have an affect on telephone and in-person surveys and that this is generally true in all types of surveys and respondents (53, 54). The impact of the incentives were found to be generally modest, though the surveys reviewed in these studies were not entirely comparable to the NCS because they did not include environmental exposure.*
>
> *In addition to the studies conducted by Church (54) and Singer (53), there has been extensive research conducted evaluating the effectiveness of various types and natures of incentives. Potential incentives that have been evaluated include: prepaid monetary incentives, gifts, promised incentives (monetary and non-monetary), lottery prizes, etc. Additionally, larger incentives have been shown to increase the response rates, though with a decreasing rate of return.*
>
> *Most of the research conducted on incentives has not been conducted within the framework of a study such as that being proposed for the NCS. In particular, studies such as the NCS, where it is of interest to collect questionnaire, biological, and environmental measurements, impose a particularly large burden on respondents*

because of the data collection requirements (e.g., requirements for personal exposure monitors, in-home sampling of environmental conditions over several days, etc.). To offset the impact that this large burden has on the response rates, survey administrators have offered substantially larger respondent incentives.

Different levels of incentives were observed in a review of nine recent studies where there was a significant amount of burden on respondents. Levels of incentives ranged from no incentive to $200 per data collection wave. Additionally, some studies employed different levels of incentive for different portions of the data collection effort.

Although the actual impact of offering an incentive to study participants is not altogether clear, prior research with other types of studies, and anecdotal evidence from recent studies that have imposed significant burden on respondents would suggest that some level of incentive be employed in the NCS. Because of the burden of the NCS, it may be necessary to consider incentives where the level of incentive increases with the length of participation and/or where an additional incentive is offered for the completion of the entire study.

Participant's Motivation/Knowledge

Informing and involving the community in a study is another potential factor that can help increase the recruitment and participation of respondents. The NCS may benefit from the sheer size of the study, national exposure through the media, and prestige of the study. Moreover, personal connections with study administrators or recruiters through hospitals/physicians and Centers of Excellence may also contribute to the success of the study in recruiting and retaining participants. However, it is not clear how much the NCS might benefit from such exposure. For example, television and radio spots yielded the fewest number of recruits in a study conducted in Minnesota (1 percent) (15), though this may have contributed to the success of recruitment of participants through other means.

G-2.2 SUMMARY OF RESPONSE RATE IN RELEVANT HISTORICAL STUDIES

The literature search yielded studies that reported initial response rates that ranged from 10% to 99%. Table 1 provides a brief summary of the response rates reported for studies identified in the literature, while Table 2 indicates the burden for each of the studies. When assessing response rates, some key aspects of the NCS that need to be taken into account are:

- High burden on the respondents
  - including environmental sampling and personal monitoring
  - length of follow-up period (20 plus years)
- Method of recruitment of
  - pregnant/pre-conception women
  - children.

Given these key aspects, an examination of Table 1 provides some insight into possible expectations.

Length of Follow-up

In Table 1 there are seven studies that did or are expected to follow participants for more than 20 years. These studies are the National Longitudinal Survey of Children and Youth (NLSCY), the three British Cohort Studies (BCS46, BCS58, and BCS70), the Collaborative Perinatal Project (CPP), the Framingham Heart Study (FHS), and the Danish National Birth Cohort (DNBC) study. Respectively, each of these studies reported initial response rates of 86%, 90%, 98%, 94%, 95%, 69%, and 60%. As a frame of reference, the CPP, BCS46, BCS58, and FHS all started somewhere in the 1940s or 1950s, the BCS70 started in 1970, the NLSCY began in 1994, and the DNBC began in 1996.

The DNBC (7, 8), which aims to recruit 100,000 women and children, will follow them for 20 plus years, with a relatively small anticipated sampling burden consisting of four or five CATI interviews, self-administered food frequency questionnaires, and some biological sampling during pregnancy. Sixty percent of all pregnant women received an invitation from their general practitioner (GP) on the first pregnancy visit. Of these women, 60% signed up to participate (i.e., the initial response rate). Because medical care is free in Denmark, more than 95% of women in Denmark see a GP or midwife for their pregnancies. Ninety-five percent of the women recruited into the study were recruited via contact with their GP.

The CPP (9-13), a center-based study that began in 1959, was conducted at 12 obstetric hospitals and followed 55,000 children from birth to adolescence. Over a 7-year period, each center used different selection methods to obtain participants for an annual two-hour exam at a medical clinic. Some hospitals selected all women in the sample frame for inclusion in the study. Other hospitals systematically selected every n^{th} pregnancy, while still others based selection on the terminal digit of the patient history number or the mother's birthday. At the time of recruitment, there were approximately 130,000 women potentially eligible for the study, 58,760 of whom met the study criteria. Of these 58,760, approximately 55,857 were recruited, yielding an initial response rate of 95%. The women were recruited into the study when they visited the participating institution for pre-natal care. The initial response rate is similar to that observed in the DBNC, even though recruitment took place more than 40 years prior in the CPP. These rates may suggest that personal relationships with physicians participating in the study are pertinent to successfully recruiting pregnant women into the study.

The NLSCY (4, 5, 6), which began in 1994, is a probability-area sample conducted in Canada. The target population is children ages 0 to 11 years of age. Two-hour telephone interviews will be used to collect information on these children every two years until age 25. The initial response rate of 86% was reported for the study and represents the number of children that completed the first set of questionnaires out of the original 22,831 selected. The initial response rate for this study is relevant to the NCS because of the longitudinal nature of the study, the number of interviews to be conducted, and the large targeted population of children. Face-to-face interviews were used to obtain information and were thought necessary to maintain high response rates.

The BCS studies are a series of physician/hospital based studies conducted in Great Britain, Wales, and Scotland. Each study followed children born during a pre-identified week

from birth through middle-age. Sampling occurred every one to two years and consisted of interviews. Pregnant or pre-conception women were recruited to participate. The response rates reported for the three BCS studies (1946, 1958, and 1970), 90%, 98%, and 94%, represent the number of achieved interviews divided by the number of eligible women who gave birth during the identified one-week period (11, 19, 27-31). The obstetricians at the hospital at which the births were to take place started advertising the study roughly one year prior to the target week of births. This appeared to help with the recruitment in the 1946 and 1970 studies with the higher response rates.

The FHS (25, 26) was a probability list sample where potential participants were middle-aged adults living in the town of Framingham, Massachusetts. Framingham was chosen for several reasons. Three key reasons were that townspeople had participated in a community study of tuberculosis 30 years prior (study coordinators felt the spirit of cooperation would still be present), the physicians/medical professions in town were very supportive of the study, and there were hospitals right in town. Participants were instructed about the longitudinal nature of the study during the recruitment process. Of the 6,507 subjects eligible to participate, 4,469 opted to participate (69%). A second volunteer phase resulted in 740 participants out of a possible 888 (83%) being recruited into the study. The explanation of the importance of the study as well as targeting an area where individuals were thought to be more receptive to participation in such a long-term study were reasons cited for successful recruitment.

Sampling/Interview Burden

Sampling/interview burden in studies is thought to be a negative in effective recruitment and retention of participants over the course of the study. As mentioned earlier, there is anticipated to be significant sampling/interview burden in the NCS. Of the studies identified in the literature, the National Human Exposure Assessment Surveys (NHEXAS-Region 5, NHEXAS-MD, and NHEXAS-AZ) are the most relevant to the NCS because of the environmental sampling conducted. Additional studies that may also be considered due to the high rate of burden are the Diana Project (Diana) and the Avon Longitudinal Study of Parents and Children {formerly the Avon Longitudinal Study of Pregnancy and Childhood}(ALSPAC). The observed initial response rates for these five studies were 72%, 35%, 79%, 7.2%, and 85%, respectively.

The NHEXAS studies (1, 2, 3) are probability-based, area sampling studies with questionnaires, food samples, biological samples, environmental samples, an activity diary, and a personal monitoring requirement that target households in the U.S. Data collection from participants occurred over a three-year period. For the NHEXAS-Region 5 and NHEXAS-AZ, the initial response rates were calculated as 72% (555 households completing the initial questionnaire out of 805 eligible) and 79% (954 completing initial questionnaire with 1,200 households approached), respectively. How the 35% for the NHEXAS-MD study was calculated could not be located. It was noted, though, for the NHEXAS-MD study, which included six measurement “cycles” over a one-year period, that the study participants were fully informed of the study requirements up front, which may have resulted in lower initial response rates but higher retention rates. The initial response rate in the NHEXAS-Region 5 was 60%. The response rate was improved to 72% by hiring a team of traveling interviewers who became very knowledgeable about the study and were able to use this knowledge to successfully recruit

participants. In addition, in the NHEXAS-Region 5 study, incentives for completion of several phases of the study were also offered. It is unclear if these incentives positively affected the initial response rate.

Pre-conception women were identified as possible participants through their HMO in the Diana project (14, 15), which was interested in following the women through birth (but not following their children). Initially, 27,400 women in a targeted age group of HMO participants in the Minneapolis-St. Paul, Minnesota area were contacted by letter, with an additional letter sent to non-responders. The letters described the sampling/interview burden of the study (office visits, self-administered monthly questionnaires, food frequency questionnaire, 7-day recall, telephone interviews), the $100 incentive for completion of the study, and eligibility requirements. Responses were obtained from 2,800 women resulting in 1,649 women who were eligible (i.e., preconception) and 1,152 who decided to participate in the study—reaching the initial goal of 1,000 participants. Thus, the CASRO response rate for this study was 7.2% (1,152 eligible and complete divided by the sum of eligible and completes {1,152}, refusals {497}, and the estimated number of eligible women among those where eligibility was not directly ascertained {1,649/2,840 * 24,560}). In addition to the letter, a variety of recruitment activities took place over a 27-month period—targeted letters, television and radio spots, referrals from health care providers, newsletters, and clinic recruitment posters. Of all the methods of recruitment, the recruitment letters yielded 72% of the individuals recruited into the study. Referrals from healthcare providers yielded 12% of the participants, announcements in HMO newsletters yielded 9%, clinic recruitment posters yielded 4%, and TV/radio ads yielded only 1% of the participants. Follow-up with the participants indicated that the $100 incentive was valued by many of them, thus encouraging higher participation.

The ALSPAC (11, 16-18) recruited pregnant women from Avon, UK, with the intent of following the children through the age of seven years, and collecting some information about the mother and partner. Local and national press, radio and TV coverage, posters, information from hospitals, and contact by physicians/midwives were all methods of recruitment in this study. The recruited women were generally informed by their GP or midwife about the study, including the burden of self-completion questionnaires for mother, child, and partner, measurements of environment sub-samples of homes, frequent hands-on assessment, in-depth interviews, annual hands-on assessment through age 7, and obtaining biological samples. A total of 14,541 pregnancies occurred during the year and a half recruitment period, with 85% of the eligible women enrolling in the study. A detailed brochure was provided to the potential participants and thought to influence, positively, the recruitment rate. The brochure emphasized the major benefits from the study to the next generation, emphasized confidentiality enforcement throughout the study, explained sampling to take place, emphasized the ability of the mother to leave the study if and when she wanted to, and provided a hotline phone number staffed by volunteers.

Method of Recruitment of Pregnant/Pre-conception Women

As seen above, the DNBC study (7, 8) and the Diana project (14, 15) recruited pre-conception women into the studies. The effective response rates in the studies were 60% and 7%, respectively. In both studies, a broad population of women was initially contacted. Also mentioned above, the CPP (9-13), ALSPAC (11, 16-18), BCS46, BCS58, and BCS70 (11, 19,

27-31) targeted women intending to give birth within a certain time frame. The initial response rates in these studies were 95%, 85%, 90%, 98%, and 94%, respectively. In all cases, the women's physician had a significant role in the recruitment process.

The Mater Misericordiae Mothers' Hospital-University of Queensland Study of Pregnancy (MUSP) was a study of 8,556 pregnant women in Brisbane, Australia (43). There was minimal burden in this study (three, 100-item questionnaires) and women were followed only through six months after delivery. Recruitment was conducted during the first antenatal clinic visit for the woman. Women who receive free antenatal care at the hospital were invited to participate during their first visit and 99% of the women invited agreed to participate. The staff prepared a questionnaire and recruitment prior to the women's visit and introduced this material during the visit.

A study by Buck et al. (14) assessed recruitment rates of studies that were concerned with recruiting women prior to conception and that had at least three months of follow-up with the women, but no follow-up with the children. The study indicated contact rates ranging from 2% up to 67% and participation rates that ranged from 42% up to 77%. Generally, letters were used as the method of recruitment, with some studies using media and some using physicians/fertility awareness clinicians. The two studies with the highest recruitment rates targeted women that had originally participated in a cohort study and targeted women at a specific company.

Method of Recruitment of Children

The Bogalusa Newborn-Infant Cohort (Bogalusa) study (11, 20) recruited all infants born within an 18-month period in Bogalusa, Louisiana. Of the 447 eligible infants, parents of 440 of the children opted to participate in the study, resulting in a 98% recruitment rate. Both hospitals and all physicians in Bogalusa were instrumental in recruitment. When a birth occurred, either the physician or the hospital called the study coordinator, who then contacted the child's family in person. The study was emphasized throughout the community by involving local community leaders. In-person interviews were conducted at recruitment.

The Early Childhood Longitudinal Study: Kindergarten Class (ECLS-K) is a probability-based study interested in understanding school readiness of kindergarten children; enrollment began in the 1998-1999 school year at selected schools (22, 23). The number of eligible students was 22,782, with 66% of the eligible children participating. Schools were first recruited for participation in the study, and then children at these schools were recruited. Seventy-four percent of the 1,277 sampled schools opted to participate. Burden consisted of telephone interviews and requests of information from the school officials. Note that incentives were given to the school for participation--$100 base and $5 per student record abstracted. Teachers were given $5 to $7 for each questionnaire they completed on a study participant.

The Framingham Children's Study (FCS) was a probability, list sample study that was intent on recruiting grandchildren of the original Framingham Heart Study (24). Children between the ages of three and five were targeted to be followed for three years. Based on a mailing to 3,534 married off-spring of the original heart study participants, 184 families responded saying they had children or grandchildren of the appropriate age to participate in the follow-up study. The requirements of the study and the duration were fully explained to the

potential participants. Fifty-eight percent (106/184) opted to participate. The burden in this study, explained to study participants prior their participation, included annual visits to the clinic for a two-hour exam, periodic food diaries, and activity monitoring for 10 days per year using an accelerometer.

G-2.3 IMPLICATIONS FOR NCS RESPONSE RATES

There are three basic approaches for recruiting women to participate in the NCS: (1) using a probability-based sampling approach, (2) employing physicians/hospitals, and (3) using Centers of Excellence. Within each of these approaches, there are several different methods that can be used to increase response rates. The specific impacts of particular methods are difficult to ascertain because of differences in target populations, sampling design, nature of the studies, etc. However, the literature does indicate that response rates can be positively influenced by:

- Informative interviewers
- Well-communicated incentives
- Good communication of the study intent (i.e., good for humanity)
- Potential participants having good relationship with participating physician
- Face-to-face interviews
- Community involvement

while the response rates can be negatively impacted by

- Intrusive sampling over a period of time
- Long interviews
- Lack of incentives.

It will be very important to factor these general observations into the design of the NCS. For example, in-person recruitment appears to be more successful than other modes of recruitment, particularly when conducted by the potential participant's physician or by a very knowledgeable, informed interviewer who can form a bond with the potential participant. Furthermore, the use of incentives to offset participant burden or the perception of burden should be employed in the NCS.

It is worthy to note that the NCS is likely to be more burdensome than the reviewed studies because of the length of the study and the extent of data collection. Therefore, the NCS might experience lower response rates than the rates presented in Table 1. On the other hand, the NCS may have higher response rates than the observed studies because of its sheer size and notoriety. However, the published literature did not provide strong evidence that community involvement such as media campaigns, advertisements, etc. will have a substantial impact on the recruitment of women, based upon a review of studies conducted in the U.S.

Several of the reviewed studies were conducted outside of the U.S. Because of differences in health care systems (i.e., generally socialized medicine), their actual recruitment rates may not be directly comparable to those observed in the U.S. Nevertheless, these studies

are important to examine because they provide valuable information on issues such as the relationships between physicians and participants, use of incentives, etc.

G-3 RETENTION RATES

In any longitudinal survey effort there will be participants who discontinue participation for a variety of reasons, which can accumulate over time and yield significantly lower overall response rates for later waves of the survey. Therefore, it is important to understand potential factors that are related to loss of participation due to attrition, and take active measures to mitigate this effect. Duncan et al. (55) suggest that the primary reasons for attrition in longitudinal surveys are refusals and failure to trace study participants. Tracing or tracking study participants, which is discussed later in this document, is therefore one method that can be used to reduce attrition. Other methods focus on preventing refusals and include items such as: incentives, in-person contact, and sending correspondence to participants for special events (holidays and birthdays, newsletters and mailings, etc.).

There is limited information on which methods are the most effective in reducing attrition. However, tracing mobile study participants is probably the single most significant activity that can be performed to reduce attrition. Marmor et al. (24) conducted a survey of participants in the Framingham Children's Study to specifically examine the survey features that were viewed by participants as important for their continued participation in the study. Results of this study indicate that "well-trained, motivated staff and personalized attention are extremely important factors in maintaining high rates of follow-up in a longitudinal study." Further, staff attitude, flexibility in scheduling, feedback to participants, quick responses to questions, and the importance of the medical research were also factors that were found to be perceived by participants as important for continuation with the study. Others have found the use of in-person visits also to be a significant factor for reducing attrition (32, 56).

Bender et al. (57) suggest that study participants' actions often provide warnings of pending dropout and that attrition can be reduced by recognizing "red flags" such as missed appointments, incomplete data, unreturned telephone calls, complaints, etc., and then increasing personal communication with these participants to prevent dropout. Others have identified a variety of different factors that have been associated with dropout, including gender, intelligence and problem solving ability, behavior problems, smoking habits, drug use, income or socio-economic status, etc. (32, 58, 15). However, the significance of these and other factors is not uniform across all studies and can vary significantly from study to study depending upon the underlying population, characteristics of the sampled participants, and the nature of the study. For the NCS, it will be important to identify factors predictive of drop-out, which can then be used to help target activities to prevent drop-out from participants.

G-3.1 SUMMARY OF RETENTION RATES FOR RELEVANT HISTORICAL STUDIES

The NCS will have multiple data collection stages requiring continued participation over many years. Therefore, both the number of initial participants and the number of participants who remain in the study after a particular data collection stage are of interest. Table 2 provides a brief summary of the retention rates among studies obtained from the literature search. As with the response rate, the reported retention rate can also be defined in several different ways. Generally, the participation rate at the end of the study, or the number of participants after a specific phase of the study is reported in Table 2.

As seen in Table 2, the reported retention rates range from 31% to 92%. Of particular interest is how these rates are affected by the length of the study, the number of times the participant must provide information, the length of time it takes to obtain the information during a sampling period, and the types of measurements that are being requested from the participants.

Length of Study

DNBC (7, 8) had a retention rate of 92% through five years of the study. As noted earlier, this may be impacted by the health care system set-up in Denmark. The FCS (24), a short study, had a 94% retention rate. The three long-term BCS studies, BCS46, BCS58, and BCS70 (11, 19, 27-31), had retention rates of 57% (after 53 years—including participants who died as retained in the study), 66% (33 years since beginning of study), and 56%, respectively.

The Bogalusa study (11, 20) required participants to complete four questionnaires within the first six months of participation with additional follow-up until 7 years of age. Free well-baby visits were offered to the mother during the child's first year as an incentive to participate. Although 61% of the mothers took advantage of the free checkups, at the six month interview 20% of the original participants had dropped out—8% because they had moved. Despite being highly publicized in the community through weekly news columns, exposure on local radio, and receipt of discount coupons to local stores, only 31% of the original participants completed the study.

Number of Requests for Information

Diana (14, 15) requested information at least every three months for four years. The information was collected through initial office visits, interviews, and monthly/quarterly self-administered questionnaires. Despite this frequent request for information, the study was able to achieve a 66% retention rate. As mentioned earlier, there was a $100 incentive for completion of the study. In addition there was a monthly newsletter, small gifts, and informative, attentive staff. The monetary incentive was deemed important by many of the women. The newsletter was started to help participants feel connected throughout the study.

ALSPAC (11, 16-18) had a retention rate of 78% for the mothers and 81% for the children, despite the fact that questionnaires were sent to the mother and child every six to ten weeks for eight to nine years. Methods used to enhance retention rates were local and national radio, television, and newspapers reporting survey results. A newsletter was sent to parents three

times a year. Health professionals in Avon received a newsletter informing them of study progress. Birthday cards were sent and a "Discovery Club" invitation with badge, folder, and other items were given to the children. Finally, to keep a high profile in the community, a member of the study staff was available to give talks to interested groups and individuals. One other factor that may have affected the retention rate was the presence of an ethics and law committee that oversaw many of the decisions made during the study—including assessing sensitivity of questions on surveys, confidentiality of information, types of biological testing, etc.

Length of Time for Each Information Gathering Period

The NLSCY (4, 5, 6) had a 66% retention rate (through cycle 4 of the study). One of the complaints of participants was that the two-hour interview, even though done at home, was too long. The MUSP study (43), with three 100-question interviews, had retention rates of 99%, 87%, and 81% of the original participants over the three phases of the study. The reasons cited for losing 19% of the initial participants by the third phase were miscarriages and failure to accurately trace patients after moves. Generally those lost to follow-up were young, single, and in the lowest income bracket.

The CPP (9-13), with questionnaires, biological samples, and medical exams (i.e., large amount of data collection), had an 84% retention rate through seven years of age for the participating children. Free medical care was given to the women as well as the children. In-person contacts were made for interviews.

Heavy Burden

With questionnaire, core monitoring activities, aerosol monitoring activities, food and beverage monitoring, and biological sampling, the NHEXAS-Region 5 (1) provided incentives for various completed tasks throughout the course of the study. Over the three visits completed in a two-year period, the response rate went from 80% to 57% to 48%. However, this decrease in response is confounded by the use of mail-back procedures for the environmental samples. NHEXAS-Region 5 included incentives that ranged from $5 for completing the baseline questionnaire to $75 for completing the food and beverage monitoring. The research team felt that higher incentives may increase participation over the whole study, but felt more strongly that decreased burden on the participants would increase participation in all phases. One suggestion was to sub-sample populations, i.e., split the extensive testing across sub-populations. In addition, the interviewing team found that if the participants agreed to the less burdensome monitoring first, they were more likely to complete the more burdensome monitoring.

The NHEXAS-MD study (2) reported a retention rate of 86%. In this study, in-person data collection was performed for all cycles. Incentives of $100 to $150 per cycle, plus $60 per food cycle, were offered. Frequent face-to-face contact may have also helped the retention rate for this study.

Other Information

Buck et al. (14) found retention rates ranging from 36% to 97% in studies with pre-conception recruitment of women. In general, use of incentives were highly correlated with high retention rates, and lack of incentives were correlated with low retention rates. In some of the studies, the burden of the study, i.e., daily diaries, appeared to be correlated with lower retention rates.

Though the Framingham Children's Study (FCS) (24) had a small sample size and a fairly small time frame, there are some interesting observations that can be made from the study. The high retention rate of 94% was thought to be due to several factors – flexible staff that communicated well, collaborative efforts between participants and researchers, thorough explanation of the expectations/demands of the study, limited geographic area, duration of clinic visits kept to a minimum, limited demands on the participants, home visits for data collection, and when appropriate, accurate record keeping of participant phone numbers and addresses. A poll of the participants indicated that reasons for leaving were divorce and moving from the area (i.e., uncontrollable events). Parents indicated they disliked having to complete the numerous food diaries and would have liked to have received more information on their results as well as the group results. They did indicate that they liked the free health care.

The Survey of Income and Program Participation (SIPP) (42) studied the effect of incentives on retention rates and found that a $10 incentive increased retention by 1% while a $20 incentive increased retention by 3%. In general, a $20 payment to retain participants outweighed the cost of repeated contacts by interviewers, and was found to be particularly successful in the high-poverty areas.

The National Cooperative Inner-City Asthma Study (NCICAS) (32), a Center of Excellence study, which focused on 1,337 four to nine year old asthmatic, inner-city children in a year long study, had a retention rate of 89% (completion of the three, three-month interval assessments). Only 40% of the children completed all three peak-flow diaries (week-long diary). It was thought that the high retention rate was due in part to recruiters obtaining two phone numbers and addresses for persons other than the primary caretaker of the child. Incentives of $50 for initial participation and $20 for each follow-up interview—not contingent on completion—were also thought to contribute to the high retention rate. Interviewers were very diligent in following up with the children and found that on average three phone calls were needed to complete the interview assessments. Reminder phone calls were placed at strategic times to encourage participation. Follow-up in-person interviews increased participation. Interviewers were more successful completing interviews when interviews took place on the weekend. Finally, whenever possible, the same interviewer performed all three interviews to maintain continuity and familiarity with the participant.

G-3.2 IMPLICATIONS TO THE NCS RETENTION RATES

Retaining participants in a longitudinal survey is sometimes more difficult than initial efforts to recruit them into the study. There are generally three types of attrition that can occur in a longitudinal study: (a) attrition because the participant is no longer representative of the population of interest (such as when a person becomes institutionalized on a long-term basis), (b) refusals, and (c) failure to track and locate study participants from one survey stage to the next. The first of these is difficult, if not impossible, to control. However, there are efforts that can be undertaken to reduce refusals and to track study participants. Several authors suggest tracking study participants as the single largest action that can be taken to reduce attrition. Many of the other methods associated with retaining participants are the same as those discussed for improving the recruitment rates, such as the use of incentives and minimizing respondent burden. Retention of study participants can also be influenced by the following:

- Testing at schools, including medical exams, particularly among school-aged children;
- Day of the week sampling occurs (e.g., offering weekend appointments) for working parents;
- Flexibility in scheduling of visits, examinations, data collection efforts, etc.;
- Knowledgeable, well-trained, motivated, and persuasive study staff that establish good rapport with participants and are persistent in obtaining responses;
- Providing personalized attention to study participants;
- Providing feedback to participants, including quick responses to questions, and results of medical tests;
- Use of in-person visits;
- Imparting a sense of partnership/ "Good for Mankind" aspect of the study to motivate participants.

Many of these, and other methods, were employed in the reviewed studies with varying success. A few of the studies had retention rates in excess of 80% over a number of years. Generally, the longer studies saw declining retention rates over time—from 31% to 57%. Possible explanations for higher retention rates in some studies, relative to others, may be excellent tracking of participants and/or the infrequent sampling/interviews required for a study. Additionally, there is some evidence that attrition by study participants is not uniform. The characteristics of participants that are lost-to-follow-up can vary significantly from study to study.

G-4 TRACKING/TRACING STUDY PARTICIPANTS

In a longitudinal study, one concern for sample attrition is participants who move and are therefore lost to follow-up. Overall, the U.S. Census Bureau estimates that roughly 46 percent of all persons aged five years or older have moved at least once between 1995 and 2000. Moreover, young adults (i.e., those persons aged 25 to 39) represented the largest segment of the migrant population between 1995 and 2000 (approximately 33 percent of all persons who moved

at least once between 1995 and 2000). However, the majority (54.2 percent) of movers between 1995 and 2000 remained within their original county of residence (59). The U.S. Census Bureau estimates indicate that roughly 16 percent to 18 percent of households will change their address during a one-year period (based upon historical estimates from 1990 to 2000), with roughly one-half of these moves occurring within the same county (60). Recent longitudinal studies have found the percentage of movers to be similar to U.S. Census Bureau estimates. For example, Brick et al. (48) found 23 percent of their participants selected for follow-up had changed their telephone number (a surrogate for moving) in a one-year period. Booth and Johnson (47) found that 41% of their initial participants had changed telephone numbers over a three-year period. In Bogalusa, 8 percent of the study participants moved within six months of the study initiation, while 32 percent had moved after seven years (20). Although the exact extent of the initial respondents that will move is unknown, it is reasonable to assume that over the course of an extended longitudinal study, such as the one being considered for the NCS, a significant percentage of the initial participants can be expected to move sometime during the study. Therefore the issue of whether to track and follow respondents that move is an important consideration for the NCS.

The Federal Committee on Statistical Methodology (61) suggests that a key consideration for determining whether to follow movers is the assessment of the most important unit of observation for the survey. In the NCS, the unit of observation is ultimately based upon the child because the overall objective of the NCS is to investigate the link between a child's environmental exposure and his/her health. So from this sense, it would be appropriate for the study to track and follow children (as they are exposed throughout their early years) because it is the child (and the child's exposure) that is of interest.

In many cases, an environmental exposure during early childhood may not result in an adverse health outcome for many months, years, or even decades. Therefore, failure to follow children who were initial study participants, but subsequently moved, may introduce bias into the survey estimates and the rates associated with some health outcomes may be over- or under-estimated. Furthermore, some of the health outcomes that are being investigated with the NCS may be relatively rare and difficult to identify. Even with a large sample size, it may still be important to follow up with some of the participants who moved to ascertain meaningful incident rates for these rare outcomes.

The relationship between mobility and the risk of health outcomes is another important consideration in the decision of whether to follow children who move. The U.S. Census Bureau (59) found that between 1995 and 2000, persons 25 through 39 years of age that have a college degree were much more likely to move than persons without a college degree, regardless of marital status. College-educated persons may benefit from a wider range of employment opportunities and more of an opportunity for higher quality health care. Therefore, they may be less at risk for adverse health outcomes during the study period than non-movers. In short, if movement by participants in the NCS is related to the likelihood of exposure and subsequent health effects, it would be important to track participants who move. Also, changes in exposures over time (related to changes in both sources and environmental concentrations) and in activities related to contact and uptake at different ages, may change risks.

Tracking participants who move is not without significant impact to the study. In particular, the costs of locating participants that move may be significant. For example, in a two-year study of 16,915 adolescents, Morrison et al. (61) report costs for tracing and completing the data collection effort to be 4-5 times greater for respondents where tracing was needed as opposed to respondents where tracing efforts were not needed. Graham and Donaldson (62) report a similar result, with the costs required to track and complete data collection being five times the costs associated with normal study procedures. This problem may be exacerbated if the study participant moves and alternative contact information is unavailable or out-of-date. Generally, the longer the time period between contact with survey participants, the more intensive the tracking and locating activities will need to be, which will incur higher costs required to locate study participants.

Another potentially significant impact on the costs may be those associated with collecting the data. Depending upon when the child's family moves and the design of the study, the costs associated with collecting data from participants that move may be significant. For example, a center-based sampling approach would tend to cluster participants geographically, facilitating the field collection of interviews and environmental measures. Participants who move a significant distance from the original geographic area, but who do not move into another geographic area that is included in the NCS sample, could require data collection expenses that would be significantly higher than those incurred for non-movers. For example, to collect an environmental measure, it might be necessary to send a separate field data collection team specifically to capture information for each family who moved, which is very inefficient. However, it may be possible to employ alternative data collection methods that would help to mitigate these additional costs (e.g., telephone interview in place of an in-person interview, mailing samplers rather than technician visits, etc.). The costs of locating and collecting data from participants who moved need to be weighed against the overall investment or costs already incurred by the NCS for that family and the timing of when the child leaves the study because of a move.

If the population of interest does not include persons that are institutionalized or reside outside of the U.S., it may not be feasible or desirable to track study participants who have become non-representative of the population of interest. Children who become institutionalized as young adults and families that move into situations where the exposure characteristics are significantly different that those typically found in the U.S. are illustrative of situations where it may not be meaningful to the study objectives to track and include these children in the study. As a specific example, consider a woman who is recruited into the NCS, participates with all data collection activities until her child is two months old, and then moves her family outside of the U.S. and remains in a foreign country for the length of the study. In this scenario, it may be meaningful to locate and collect information from this child for certain health endpoints that are associated with exposure pre- and immediately post-birth, but it may not be meaningful to collect information for other health outcomes that are associated with exposure in early childhood.

Because of the size and duration of the NCS, there will be a significant portion of the NCS sample that will move during the study period. There are benefits and costs associated with locating and collecting data from these study participants. The determination of whether to follow all movers, some movers, or not to follow any movers depends upon several factors. The

following questions outline the salient issues that should be considered when determining whether to follow respondents that move:

- Are the health outcomes of interest rare or require many years for diagnosis?
- Do movers represent a "rare" population of interest?
- Are the characteristics of movers generally different than those of non-movers so that there is a plausible relationship between mobility and health outcome?
- Are respondents that move still representative of the population of interest?
- Can tracing or locating participants that move be completed within reasonable costs?
- Can data collection from participants who move be completed within reasonable costs?

For the NCS, responses to the first four questions would suggest that movers should be followed and data collection should be continued from these participants. Answers to the remaining two questions still need to be ascertained, and may vary from respondent to respondent and by data collection method. For example, roughly 46 percent of all persons aged five or older who moved at least once between 1995 and 2000 moved within the same county (59). Thus, these participants may still be in the catchment area of a medical center and data collection costs for these respondents may not be significantly increased from non-movers if a data collection approach based upon a medical center is employed.

G-4.1 EFFECTIVENESS OF TRACKING/TRACING STUDY PARTICIPANTS

Tracing and tracking respondents has been widely employed in survey research in a variety of different fashions with generally good success. Burgess et al. (63) suggest that survey researchers should expect to locate at least 80 percent of participants and that rates of 90 percent or higher can be achieved. A review of several studies conducted in the 1980s and 1990s where tracing methods have been employed supports this supposition (see Table 3).

Even under difficult conditions, researchers have been able to successfully locate a high percentage of study participants. For example, in the NHANES I Epidemiologic Follow-up Study, there was no contact with study participants for 8-10 years following the initial data collection effort, but 93 percent of all study participants were still successfully located (64), though not without considerable effort and costs. Booth and Johnson (47) report being able to locate 66 percent of respondents who changed their telephone number, including one-half of participants who changed their telephone number but did not provide a name or address. This is significant because this study was conducted using telephone interview methods. In another telephone-based study, Brick et al. (48) report successfully locating 83 percent of study participants after one year who did not provide address information, and 49 percent of participants that did not have the same telephone number. Again, these cases represent participants that are among the most difficult to locate because of a limited amount of information that can be used to conduct the tracing.

A variety of different methods have historically been employed by a number of studies (see Table 3) to locate study participants. Some of these methods are simple and cost-effective,

such as telephoning the last known number, using crisscross directories to identify former neighbors and contacting them via telephone for contact information, postcards requesting forwarding address information, etc. Others are more time-consuming and expensive, such as conducting field visits to last known address and contacting neighbors. Goldstein (65) suggests using a hierarchical framework for tracing study participants whereby methods that are relatively inexpensive are employed first, followed by more extensive and expensive methods for cases that are not resolved. A similar framework for conducting tracing methods should be adopted for the NCS.

Many of the tracing methods are used in conjunction with each other, making it difficult to determine the specific effectiveness of each tracing method. However, two techniques are often suggested as the most effective: (a) collecting contact information from an alternative contact person(s), and (b) making periodic contact with survey participants.

In a specific study conducted to investigate the effectiveness of two alternative tracing methodologies, including the use of alternative contact persons and commercial credit reports, Hahn et al. (66) concluded that the "single most effective procedure in participant tracing was the use of contact persons." Others have reported similar findings regarding the effectiveness of alternative contact persons (67, 68). Collecting contact information from alternative contacts is effective because it provides a relatively low-cost opportunity to obtain new information on the whereabouts of study participants that have moved since the last data collection effort. Because alternative contact persons also move, the effectiveness of using an alternative contact person can be improved by asking study participants to provide more than one alternative contact. Senturia et al. (32) found that there was a significant relationship between the number of alternative contacts provided and the percentage of participants with complete follow-up.

The Forward Trace Study (69, 70) was a methodological study conducted by the U.S. Census Bureau in the early 1980s to investigate the coverage of the 1980 census. However, the study focused on the effectiveness of three tracing methods: (a) periodic tracing with intermediate personal contact, (b) periodic tracing with one initial contact, and (c) periodic tracing without personal contact, which were compared on costs and the final rate of locating respondents. The study was conducted over a four-year period beginning in 1980. The results of the study indicate that "tracing with personal contact was more successful than tracing without personal contact." A comparison of the relative costs indicates that tracing with personal contact was more expensive due to the intermediate interviewing costs than either of the other two methods. However, as the length of time between sampling intervals increases, maintaining periodic contact with study participants to update contact information becomes more cost-effective than retrospectively tracing study participants (63).

As discussed previously, a large segment of study participants will move during the study period, necessitating tracing/tracking of these respondents if it is desired that they continue to be included in the study. The following guiding principles should be considered when developing the specific methodology for tracing/tracking that will be employed in the NCS:

- Collect information on one or more alternative contact persons as part of the initial interviewing process.

- Maintain periodic contact with study participants for the purposes of encouraging their participation and obtain updates to contact information proactively, including information on alternative contacts.
- Conduct tracing/tracking using a hierarchical methodology beginning with the least expensive methods.

G-4.2 TRACKING NON-RESPONDING PARTICIPANTS

In many respects, the issues associated with tracking non-responding participants are similar to those for tracking participants that move. For example, moving may be one underlying reason for not participating in the study. However, for the purposes of the following discussion, it is assumed that non-responding participants have refused to participate in the study, either explicitly or implicitly, through their actions. Thus, the primary issue for this group of study participants becomes not one of locating them, but whether they can be converted back into study participants once they are located.

Refusal conversion has long been conducted as part of survey operations and can be an effective means for obtaining information from reluctant participants. Refusal conversions are much less effective with "hard" refusals, or those participants that have indicated a strong desire for removal from the study. Tracking and attempting data collection from these participants may not be fruitful, and may raise ethical concerns. However, tracking and attempting to convert reluctant participants, where there is a larger possibility that they can be converted back into study participants is an appropriate consideration for the NCS.

Drop-out from participation in a longitudinal study such as the NCS may be impacted by many factors, including major life events such as birth, adoption, divorce, changing jobs, etc. Over time, as these issues are resolved by family members, participation in the study may again be an option for the household/child (57). Turner and Le Souef (71) found that "…parents had refused to let their child participate at 6 years, but were agreeable five years later, suggesting that parents of younger children are less likely to allow participation in research studies." This would suggest that following and contacting non-responding participants may result in re-participation in the study.

One concern in a longitudinal study in tracing and tracking of non-responding participants is the quality of the responses that are obtained from the converted participants. In some cases, it is possible to "over-do" the conversion activity. While this may result in the ability to collect information from the "converted" respondent, the respondent's responses and level of participation would indicate that they continue to be "soft" refusals and are providing answers only to relieve themselves of the burden of the conversion activity. Nevertheless, while they may not participate in all measurements, they might still provide some information that would allow for assessing differences with study participants (i.e., facilitating an assessment of bias).

Another concern with tracking non-responding participants is that this activity requires study resources. As discussed above, anecdotal evidence would suggest that this activity would

be warranted for some portion of the non-participating households, particularly those that are non-participants because of a move, major life event, or are otherwise "soft" in their refusal to participate. However, one significant question would be to determine the appropriate length of time to track and follow non-responders. For example, in the Survey of Income and Program Participation (SIPP) non-respondents are followed for two or three data collection efforts depending upon the type of non-response before follow-up efforts are discontinued (72). A similar technique could be employed in the NCS. That is, follow non-responders for several data collection waves, but discontinue if there is continued non-response for sequential waves. An alternative would be to continue to follow non-responders for an extended period of time, but employ only those tracing/tracking procedures that can be completed with minimal additional costs. Periodic attempts could then be made as the child ages to convert the household into re-entering the study.

An additional consideration of whether to follow non-responding participants concerns the data collection activity that was missed. In particular, if a critical measure cannot be obtained because the participant did not respond for a specific data collection effort, it would not be cost-effective or scientifically logical to continue to attempt to include the participant in the study. For example, if there were critical baseline biological samples that need to be collected prior to the birth of the child to assess a particular health outcome, but these data were not collected, it would not make sense to conduct further data collection efforts with this participant unless he/she can provide information on some other important health outcomes. However, there are a number of different outcomes and associated "critical" measures in the NCS, so this may be less of a concern for the NCS than in other studies with fewer measures. For example, participants may be willing to provide indoor/outdoor air and lung function measurements related to asthma, but not urine or pesticide usage information an psycho/social measures. These participants may still be desirable to keep in the study because they provide information for asthma, even though they do not provide information that can be used to evaluate neurodevelopmental outcomes.

G-4.3 ALTERNATIVES TO TRACING/TRACKING

Tracking and tracing efforts may be successful at locating many of the study participants who have moved or who were non-responders for a particular data collection effort. However, locating respondents is not necessarily equivalent to obtaining completed interviews from those respondents. Additionally, there will be some study participants who will never be located. Therefore, it is likely that methods other than tracking/tracing will need to be employed to reduce bias associated with the loss of these participants. McGuigan et al. (73) suggest that because other methods need to be employed anyway, it could be appropriate to reduce the tracking/tracing efforts in favor of alternative methods.

Generally, there are three types of methods that are employed to adjust for attrition in a longitudinal survey: weighting adjustments, imputation, and modeling activities. Weighting adjustments employ techniques such as inverse propensity score weighting (73) or weighting cell adjustments (74). Imputation involves formulation of a model to generate likely responses to missing information based upon the patterns and characteristics of responders (77). Other

modeling activities can also be employed such as the Heckman Sample Selection Model (75), which develops an additional covariate related to the probability of participating that is used in subsequent modeling efforts.

All of these methods are conducted after data have already been collected, and can be inexpensive relative to the costs of data collection. Simulation studies have provided some evidence that these methods provide estimates that agree with those that would be obtained if all participants responded (73). However, all of these methods suffer from the fact that they require assumptions to be made regarding non-responders and it is very difficult to validate these assumptions without obtaining information from the non-responders themselves. Therefore, while these methods will likely be employed in the NCS, they should be employed in addition to tracking and tracing of participants.

G-5 SUMMARY

This paper provides information on recruitment and retention methods, historical rates, and information on tracing/tracking techniques that are useful for the formulation of design options for the NCS. A review of the published literature did not yield any one study that would provide definitive guidance for the expected response or retention rates in the NCS. However, many of the identified studies do provide some general information that is useful to consider when developing options for the design of the NCS.

G-5.1 RESPONSE RATES

Recruitment of women to participate in the NCS will be challenging. Because of the nature of pregnancy planning, this will be especially true for identifying and recruiting pre-conception women. A variety of different methods have been employed to identify women for participation in longitudinal studies. In particular, all three approaches under consideration for the NCS—physician/hospital, probability, and center-based recruitment—have been employed. Within each of these approaches, there are several different methods that can be used to increase response rates. The literature would suggest that these methods have been successfully employed in all three approaches to obtain the participation of women/household for a longitudinal survey. The literature search yielded studies that reported initial response rates that ranged from 10% to 99%. No single approach seemed to conclusively stand out as more effective than another approach, though it is noteworthy that only two studies that employed a center-based approach were reviewed. Moreover, it does appear that a probability-based approach can be effective in recruiting participants, even in surveys with significant respondent burden such as the NHEXAS studies (1, 2, 3) – though it is also important to note that these studies were not long-term studies, and did not involve health measures.

The specific impacts of particular methods are difficult to ascertain because of differences in target populations, sampling design, nature of the studies, etc. However, the literature does indicate that response rates can be positively influenced by:

- Informative interviewers

- Well-communicated incentives
- Good communication of the study intent (i.e., good for humanity)
- Potential participants having good relationship with participating physician
- Face-to-face interviews
- Community involvement

while the response rates can be negatively impacted by

- Intrusive sampling over a period of time
- Long interviews
- Lack of incentives.

It will be very important to factor these general observations into the design of the NCS. For example, the use of incentives to offset participant burden or the perception of burden should be employed in the NCS. In-person recruitment appears to be more successful than other modes of recruitment, particularly when conducted by the potential participant's physician or by a very knowledgeable, informed interviewer who can form a bond with the potential participant. An inherent trust and bond between potential participants and their physician or a medical Center of Excellence is one primary reason why a center or physician-based approach is more appealing than a probability-based approach (where the relationship has to be developed essentially from scratch). If a probability-based approach is employed, it will be critical to provide recruiters with in-depth knowledge of the study, and to minimize turnover in the recruitment/data collection staff – facilitating the growth of a rapport between participant and data collector.

It is noteworthy that the NCS is likely to be more burdensome than the reviewed studies because of the length of the study and the extent of data collection. Therefore, the NCS might experience lower response rates than the rates presented in Table 1. On the other hand, the NCS may have higher response rates than the observed studies because of its sheer size and notoriety. However, the published literature did not provide strong evidence that community involvement such as media campaigns, advertisements, etc. will have a substantial impact on the recruitment of women, based upon a review of studies conducted in the U.S.

G-5.2 RETENTION RATES

Retention of parents and children in the NCS will be almost, if not more, challenging than the initial recruitment due to the length of the follow-up period and the extent of the data collection effort. Because of design differences, it is difficult to compare retention rates between studies. Nevertheless, no single method of recruitment seemed to result in uniformly higher retention rates and the retention rates among the observed studies varied significantly with reported rates ranging from 31% to 92%. A few of the studies had retention rates in excess of 80% over many years. Generally, however, the longer studies saw declining retention rates over time—from 31% to 57%. Other possible explanations for higher retention rates in some studies, relative to others, may be excellent tracking of participants, which is cited by several authors as the single largest action that can be taken to reduce attrition, and differences in frequency sampling/interviews required in the various studies. Many of the methods associated with

retaining participants are the same as those discussed for improving the recruitment rates, such as the use of incentives and minimizing respondent burden. Retention of study participants can also be influenced by the following:

- Testing at schools, including medical exams, particularly among school-aged children;
- Day of the week sampling occurs (e.g., offering weekend appointments) for working parents;
- Flexibility in scheduling of visits, examinations, data collection efforts, etc.;
- Knowledgeable, well-trained, motivated, and persuasive study staff that establish good rapport with participants and are persistent in obtaining responses;
- Providing personalized attention to study participants;
- Providing feedback to participants, including quick responses to questions, and results of medical tests;
- Use of in-person visits;
- Imparting a sense of partnership/ "Good for Mankind" aspect of the study to motivate participants.

Again, none of the studies reviewed employed exactly the same scope, size, and design as that being considered for the NCS. Differences in the identified studies include: much smaller sample sizes, lower burden on respondent, absence of the collection of environmental samples, geographically smaller areas, etc. Therefore, the retention rates observed in the reviewed studies may be higher than the retention rates that would be obtained in the NCS.

G-5.3 TRACKING/TRACING STUDY PARTICIPANTS

Determining whether to track/trace study participants that move or are non-responders depends upon responses to several questions including:

- Are the health outcomes of interest rare or require many years for diagnosis?
- Do movers represent a "rare" population of interest?
- Are the characteristics of movers generally different than those of non-movers so that there is a plausible relationship between mobility and health outcome?
- Are respondents that move still representative of the population of interest?
- Can tracing or locating movers be completed within reasonable costs?
- Can data collection from persons who move be completed within reasonable costs?

For the NCS, the first four questions would suggest that movers should be followed and data collection should be continued from these participants. Many of the moves made by survey participants will be within their same county of residence so the costs of collecting data from these participants may not be greatly increased. Regardless, given the extent of the population that can be expected to move within the follow-up period, it is apparent that some degree of tracking/tracing will need to be conducted as part of NCS data collection procedures.

Tracking/tracing methods can successfully locate study participants, with many studies locating 80% to 95% of all study participants, though this process can be costly to implement; costs of 4-5 times the "normal" costs of data collection should not be unexpected. These costs can be reduced through obtaining the name of alternative contact person(s) during the initial interview and maintaining routine contact throughout the data collection period.

Table G-1. Summary of Response Rates Observed in Studies Conducted Over the Last 50 Years

Study [Reference]	Types of Measurements[a]	Sampling Method	Number of Participants	Initial Response Rate	Notes
NHEXAS Region 5 [1]	Q, F, E, B, Diary	Probability – Area Sampling	555	72%	- Response rate for initial questionnaire - 555 households completed/805 eligible
NHEXAS Maryland [2, 44]	Q, F, E, B, Diary	Probability – Area Sampling	80	35%	- Respondents were fully informed of study requirements
NHEXAS Arizona [3]	Q, F, E, B, Diary	Probability – Area Sampling	954	79%	- 954 households participated with initial questionnaire of approximately 1200 approached
NLSCY [4, 5, 6, 78, 79]	Q, Skill assessment	Probability Area Sampling	22,831	86%	- Response rate for 1st cycle - Study conducted in Canada
DNBC [7, 8]	Q, B	Physician	60,000+	60%	- 60% of women invited to participate - 60% of those invited to participate did so - Study conducted in Denmark
CPP [9, 10, 11, 12, 13, 44]	Q,B, Medical Exam	Center-based	55,908	95%	- 58,760 cases met study criteria, 53,039 were registered - Study conducted at 12 centers - Each center used different selection methods
Diana [14, 15]	Q, B, Medical Exam	Hospital/Physician	1152	7.2%	- Study conducted in an HMO in Twin Cities, MN - 27,400 women were contacted, 2800 responded, 1649 eligible - 70% of eligible women completed
ALSPAC [16, 11, 17, 18]	B, Observational, Medical Exam	Hospital/Physician	14,541	85%	- Number represents the enrollment rate of eligible mothers - Volunteer enrollment - Conducted in Avon, UK
BCS46 11, 27, 28	Q, B, Medical Exam	Physician	13,687	90%	- Study conducted in UK - Response rate is based upon initial interviews of eligible pregnant women who gave birth in a 1 week period - 5362 births identified and followed
BCS58 [29, 30, 31, 19]	Q, Medical Exam	Hospital	15,147	98%	- Number achieved interviews divided by number of initial sample cohort members - Children born March 3-9, 1958 in Great Britain. - Immigrants born during same week were added at ages 7, 11, and 16.
BCS70 [19]	Q,	Hospital	16,135	93.8%	- 16,135 people completed interviews from 17,198 eligible - All births in a 1-week window were eligible - Conducted in the UK
Bogalusa [11, 20]	Q, B, Medical Exam	Hospital/Physician	440	98.4%	- 440 participated from 447 eligible - Conducted in Bogalusa, LA
Boston NO_2 [21]	E	Probability	501	60%	- Study conducted in Boston - 581 households participated out of 973 eligible

Table G-1. Summary of Response Rates Observed in Studies Conducted Over the Last 50 Years

Study [Reference]	Types of Measurements[a]	Sampling Method	Number of Participants	Initial Response Rate	Notes
ECLS-K [23,22, 80]	Q, School records	Probability – schools	22,782	66%	- 74% of 1277 sampled schools participated; 89.8% of children
Framingham Children's Study [24]	B, Medical Exams, Diary	Non-probability – family history w/study	106	58%	- number represents participation rate of 106 volunteer participants out of 184 potentially eligible - Relatives of previous Framingham Heart Study- Phase II participants - Study conducted in Framingham, MA
Framingham Heart Study [25, 26]	B, Medical Exams, Medical history	Probability- list sample augmented with volunteers	5209	68.7%	- 6507 initial subjects were eligible to participate, 4469 participated - Supplemental volunteer sample of 740 participants, not included in RR calc
NCICAS [32]	Q	Center of Excellence	1,337		- One center excluded in sample size due to administrative problems - On contact, collected phone and address for two alternate contacts.
NHANES I [33, 34, 81]	Q, B, Medical Exam	Probability	28,043	99%	- 20,749 of original set of responses (28, 043) were examined. - Medical and biological were given to a subset of the households
NHANES II [35, 81]	Q, B, Medical Exam	Probability		91	
NHANES III [35, 36, 81]	Q, B, Medical Exam	Probability	20,277	83%	- Represents the number that successfully completed the initial interview
NHSDA [37, 38]	Q	Probability	3200 (1971) 25,000 (1998)	93% annually	
NSAF [39, 40]	Q	Probability	483,260	Ranged from 77% to 78%	- RDD used to identify households with telephones - Represents those interviewed divided by those selected
Tucson EPI [41]	Q, B, Medical Exam	Probability	2989	55%	- 1655 households out of 2989 households participated. 3805 individuals out of households participated.
SIPP [42]	Q	Probability	39,600	92%	- Number of initial interviews in Wave 1
MUSP [43, 82]	Q	Physician/Hospital	8,556	99%	

a. Q = Questionnaire; F = Food Samples; E = Environmental Samples; B = Biological Samples

Table G-2. Summary of Retention Rates Observed in Studies Conducted Over the Last 50 Years

Study [Reference]	Burden					Incentives	Retention Rate	Notes
	No. of Visits	Time Period	Length of Interview	Where Conducted	Personal Requirements			
NHEXAS Regions [1]	3	2 yr	1-3 hrs	Home (In-person) and (mail back)	Personal Monitor	$5-$75 (increases for more burdensome measures)	28.4%	- Mail back methods used in later visits, which could have impacted the response rates in later cycles
NHEXAS MD [2, 44]	6	1 yr		Home (In-person)	Personal Monitor	$100-$150 per visit (increases with number of visits) plus $60/visit for food	86%	- In-person data collection used for all cycles - Some households participated in all cycles
NHEXAS – Arizona [3]	3			Home (In-person)	Personal Monitor	Monetary		
NLSCY [4, 5, 6, 78, 79]	5	8 yrs	2 hrs	Home (CATI/CAPS)	None	Unknown	66%	- Retention rate through cycle 4 (2001)
DNBC [7, 8]	4	2-4 yrs	10-15 min	Home (CATI)	None	None	92%	
CPP [9, 10, 11, 12, 13,44]	6	7 yrs	2 hrs	Clinic	None	Intangibles	84%	- Study conducted 1959-1974
Diana [14, 15]	12	4 yrs	15-20 min	Clinic	None	$100 total, small gifts	66%	
ALSPAC [16, 17, 18, 11]	40-54	9 years		Self-reported via mail and school	None	Non-monetary small gifts	78% mothers, 81% children	- number presented is the 4-yr cumulative response rate - questionnaires sent every 6-10 weeks for 8-9 years
BCS46 [11, 27, 28]	18	53 yrs		Homes, school, clinic			72% after 4 yrs 57% after 53 yrs	
BCS58 [29, 30, 31, 19]	6	33 yrs	15 min to 1.5 hrs	Home	None	None	66%	- Collection occurred at birth (1958), 5, 11, 16, 23, and 33 yrs
BCS70 [19]	5	26 yrs		Home	None	None	56%	- 9,003 of the original 16,135
Bogalusa [11, 20]	9	7 yrs		Self in home, clinic, school	Fasting	Non-monetary; free medical care	30.5%	- Retention rates at 7 yrs - 134 of 440 participants completed the 7-yr data collection
Boston NO_2 [21]	3	1 yr		In home mail back	None	None	83%	- 417 households out of 501 completed all three sampling periods

Table G-2. Summary of Retention Rates Observed in Studies Conducted Over the Last 50 Years

Study [Reference]	Burden					Incentives	Retention Rate	Notes
	No. of Visits	Time Period	Length of Interview	Where Conducted	Personal Requirements			
ECLS-K [23, 22, 80]	At least once a year from children	6-7 yrs		Schools Home-telephone	None	$5-$7 teachers $100 base+ $5 per student record abstract Children received non-monetary gift		
Framingham Children's Study [24]	3	3 yrs	2 hrs	Clinic, Home	Monitor	Small non-monetary	94%	- Data was collected on 100 of 106 children. - Periodic food diaries.
Framingham Heart Study [25, 26]	25 (every 2 yrs)	50 yrs		Clinic	Monitor			- In 1998, 1095 of the original 5209 alive and well.
NCICAS [32]	3	~1 yr	10 min	Home	Food diary	$50 baseline interview; $20 each follow-up interview; small non-monetary	89%	- 40% completed all 3 diaries - On average, 3 phone calls to complete follow-up interview.
NHANES I [33, 34, 81]	1			Mobile exam centers (near home)	None	$10 honorarium	76.4% with incentive; 68.1% with no incentive	- The incentive retention information is a sub-study of 13,370 participants.
NHANES II [35, 81]	1			Mobile exam centers (near home)	None		80%	
NHANES III [35, 36, 81]	1	3		Mobile exam centers (near home)	Physical activity monitor (7 days)	Free medical exam; selected participants received monetary and non-monetary incentives	74%	- Following the mobile exam center visit - When there were more invasive tests such as fundus photography and bone densitometry this resulted in lower participation rates.
NHSDA [37, 38]	1			Home			78% on average	- Annual survey - Represents those that were interviewed after the initial screen.
NSAF [39, 40]	1			Home	None			

Table G-2. Summary of Retention Rates Observed in Studies Conducted Over the Last 50 Years

Study [Reference]	Burden					Incentives	Retention Rate	Notes
	No. of Visits	Time Period	Length of Interview	Where Conducted	Personal Requirements			
Tucson EPI [41]	1		25 min	Home or clinic	None			- 98% completed questionnaire - 96% completed flow volume assessment - 94% allowed blood samples to be taken - 96% allowed allergy test to be performed.
SIPP [42]	6	2 yrs		Home	None	$10/$20	72% without incentive 73% with $10 incentive 75% with $20 incentive	- $20 incentive was effective in lowering non-response and reduced number of interviewer visits. Particularly successful in high poverty stratum; Saw a 3% increase in response over all 6 waves
MUSP [43, 82]	4	1 yr	~100 questions per survey	Clinic/home	None		81%	- Failure to trace - 87% of women completed phase II. Reason for fall in response rates were miscarriages or leaving area.

Table G-3. Summary of Tracing Methods Used in Longitudinal Studies

Author(s)	Year Of Initial Survey / Year of Follow-up Survey	Frequency of Follow-up Procedures	Number of Initial Participants	Tracing/Tracking Methods	Most Useful Tracing/ Tracking Method	Percent Located
Booth and Johnson (47)	1980 / 1983	Some measures each year	2,033	• Telephone last known number (updated through follow-up) • Telephone "similar" numbers • Request contact information on former holder from current holders of telephone number • Directory assistance in same community • Using contact persons provided by respondents • Public libraries to look up names in city directories • Call people with similar or same last names in community • Letters to last known address	Telephone last known number and contact persons	86%
Brick et al. (48) [Feasibility Study for the National Household Education Survey]	1991 / 1992	One Year After Initial Survey	513	• Postcards requesting forwarding address information • Called telephone number used in initial survey • Utilized participants' recorded messages with new telephone number • Directory assistance • Called contact person identified by survey participant • Credit reporting service	Unclear – not credit reporting service	88%
Hogan (69) Mulry and Dajani (70) [The Forward Trace Study]	1980 / 1984	A: Periodic with Personal Contact B: Periodic with only Initial Contact C: Periodic without contact	A: 1,862 B: 3,309 C: 3,577	• Post Office confirm address/forwarding address • Letters with address correction requested • Interim interview (Group A) to update records • Administrative record match to IRS files • In-person field visit • In-person "Super Trace"	Intermediate Personal Contact	A: 87% B: 81% C: 83%
Morrison et al. (61)	Late 1990's / 2 years after initial	2 Years	16,915	• Called telephone number recorded in initial interview • Review clinician's records • USPS certified letter • CD-Rom and reverse telephone directory to contact participant's former neighbors and/or relatives • Contacted parents at work	Calling the initial telephone number followed by clinician records	93%

Table G-3. Summary of Tracing Methods Used in Longitudinal Studies

Author(s)	Year Of Initial Survey / Year of Follow-up Survey	Frequency of Follow-up Procedures	Number of Initial Participants	Tracing/Tracking Methods	Most Useful Tracing/ Tracking Method	Percent Located
Bachrach et al. (76) [1995 National Survey of Family Growth]	1993 1995	2 Years	14,000	• U.S. National Change of Address System (NCOA) • Telematch • Contact last known telephone number • Tracing contractor • Postcard with request for change of address • Field visits to last known address and neighbors • Address Information Request Form to area postmaster • Directory Assistance • Telephoning contact person supplied in initial interview • Department of Motor Vehicle database match • TransUnion interactive database match	Unknown	95%
Hahn et al. (66)	1982-1983 1986-1987	4 years	622	• Contact person • Drivers license bureau • Last known place of employment • Field visit to original address • Credit services	Contact Person	96%
Cox et al. (64) [NHANES I Epidemiologic Follow-up Study]	1974 1982-1984 1986 1987 1992	8-10 years 2 years 1 year 5 years	14,407 3,980 11,750 11,195	• Postal services address correction forms • National Death Index • Social Security Administration Mortality File • Telematch • Last confirmed telephone number • Directory Assistance • Contact person provided by respondent • Contacting a former neighbor • Department of Motor Vehicle database matches	Unknown	93% 95% 94% 90%
Senturia et al. (32) [National Cooperative Inner-City Asthma Study]	Mid-1990's 3, 6, 9 months	Every 6 Weeks	1,337	• Directory Assistance • Reverse directory for last known address • Calling contact person • Letter to last known address with a forward request • Letter to contact person • Reviewing hospital databases for last known address • Certified mail to determine residency	Unknown	93% 94% 95%

G-6 REFERENCES

1 Whitmore RW, Byron MZ Clayton CA, Thomas KW, Zelon HS, Pellizzari ED, Lioy PJ, and Quackenboss JJ. 1999. Sampling Design, Response Rates, and Analysis Rates for the National Human Exposure Assessment Survey (NHEXAS) in EPA Region 5. *J. Exposure Anal. and Env. Epid.* 9: 369–380.

2 Callahan MA, Clickner RP, Whitmore RW, Kalton G, Sexton K. 1995. Overview of Important Design Issues for a National Human Exposure Assessment Survey. *J. Exposure Anal. and Env. Epid.* 5, no. 3: 257–282.

3 Robertson, et.al. 1999. The National Human Exposure Assessment Survey (NHEXAS) Study in Arizona-Introduction and Preliminary Results. *Exposure Anal. and Env. Epid.* 5, No. 3:

4 http://www.statcan.ca/english/sdds/4450.htm

5 Michaud S. 1999. The National Longitudinal Survey-Overview and Changes After Three Cycles. *Paper presented at Workshop on Longitudinal Research in Social Science.* October 25-27.

6 Brodeur M; Montigny G; Berard H. 1995. Challenges in developing the National Longitudinal Survey of Children (Disc: p39-41). *American Statistical Association Proceedings of the Section on Survey Research Methods*, 21–28.

7 Olsen J, Melbye M, Olsen SF, Sorensen TI, Aaby P, et al. 2001. The Danish National Birth Cohort – its background, structure, and aim. *Scand. J. Public Health* 29 (December): 300-307.

8 www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11775787&dopt=Abstract

9 U.S Department of Health Education and Welfare, Public Health Service, National Institutes of Health. 1972. *The Collaborative Perinatal Study of the National Institute of Neurological Diseases and Stroke: The Women and Their Pregnancies* DHEW Publication No. (NIH) 73-379). http://www.archives.gov/research_room/center_for_electronic_records/national_institutes of health.html

10 National Institutes of Health. 1983. *Collaborative Perinatal Project*, 1958-1974. http://www.nber.org/cpp/docs/cpp-vol1.pdf

11 The Lewin Group. 2001. *Cohort identification and Recruitment Planning for the Proposed Federal Longitudinal Study on Environmental Risk and Child Health.* Technical Report prepared by The Lewin Group Under Contract Number HHs-100-97-0016 for the National Center for Health Statistics, Centers for Disease Control and Prevention. May 16, 2001.

12 Niswander KR and Gordon M. 1972. *The Collaborative Perinatal Study of the National Institute of Neurological Diseases and Stroke: The Women and Their Pregnancies.* U.S. Govt. Printing Office. DHEW Publication No. (NIH) 73-379. 540 pp.

13 Burke J, Le T, and Brick JM. 1998. Sample Design Issues for the Base Year of a Longitudinal Survey of Kindergarten Children. *American Statistical Association Proceedings of the Section on Survey Research Methods.* pp. 715-720.

14 Buck G, Lynch C, Stanford J, Sweeney A, Schieve L, Rockett J, Selevan S, and Schrader S. 2003. Prospective pregnancy study designs for assessing reproductive and developmental toxicants. *Environmental Health Perspectives.* Accepted.

15 Brown J, Jacobs D, Barosso G, Potter J, Hannan P, Kopher R, Rourke M, Hatrman T, Hase K. 1997. Recruitment, retention, and characteristics of women in a prospective study of preconceptional risks to reproductive outcomes: experience of the Diana Project. *Paediatric and Perinatal Epidemiology*. 11: 345–358.

16 http://www.alspac.bris.ac.uk/elspac/Default.shtm

17 Golding, J. 1990. Children of the Nineties: A Longitudinal Study of Pregnancy and Childhood based on the population of Avon (ALSPAC). *West of England* Medical *Journal* 105: 80 – 82.

18 Mumford S. 1999. Children of the Nineties: Challenges for the Ethics and Law Committee. *Archives of Disease in Childhood: Fetal and Neonatal Edition* 81: F228-F231.

19 Makepeace G, Dolton P. 2003. What can the National Child Development Study (NCDS) and the 1970 British Birth Cohort Study (BCS70) tell us about the individual's acquisition and use of education and training? *Research Review for the Qualifications and Curriculum Authority.*

20 Webber L, Frank G, Smoak C, Freedman D, and Berenson G. 1987. Cardiovascular Risk Factors From Birth to 7 Years of Age: The Bogalusa Heart Study, Design and Participation. *Pediatrics* 80: 767-78.

21 Ryan P, Soczek M, Treitman R, Spengler J, and Billick I. 1988. The Boston Residential NO2 Characterization Study: Survey Methodology and Population Concentration Estimates. *Atmospheric Environment* 22, no. 10: 2115 – 2125.

22 http://nces.ed.gov/ecls

23 Burke J; Le T; Brick J. 1998. Sample Design Issues for the Base Year of a Longitudinal Survey of Kindergarten Children. *American Statistical Association Proceedings of the Section on Survey Research Methods*, 715- 720.

24 Marmor J, Oliveria S, Donahue R, Garrahie E, White M, Moore L, Ellison R. 1991. Factors Encouraging Cohort Maintenance in a Longitudinal Study. *Journal Of Clinical Epidemiology* 44, No. 6: 531-535.

25 D'Agostino R, Kannel W. 1989. Epidemiological background and design: The Framingham Study. *ASA Sesquicentennial Invited Paper Sessions, M. Gail and N. L. Johnson (Eds.), American Statistical Association, Alexandria, Virginia, U. S. A.* 707-718.

26 Department of Health and Human Services, National Institute of Health, National Heart, Lung, and Blood Institute. 2002. Framingham Heart Study. http://www.nhlbi.nih.gov/about/framingham/

27 http://www.med.ic.ac.uk/divisions/60/euroblcs/mrcbirth.htm

28 Richards M, Hardy R, Kuh D, Wadsworth ME. 2001. Birth weight and cognitive function in the British 1946 birth cohort: longitudinal population based study. *British Medical Journal* 322: 199-203.

29 http://www.nationalstatistics.gov.uk/StatBase/Source.asp?vlnk=1316&More=Y

30 Power C, Hertzman C, Matthews S, Manor O. 1997. Social Differences in Health: Life Cycle Effects between Ages 23 and 33 in the 1958 British Birth Cohort. *American Journal of Public Health* 87: 1499-1503.

31 http://www.cls.ioe.ac.uk/Cohort/Ncds2000/mainncds00.htm

32 Senturia Y, Mortimer K, Baker D, Gergen P, Mitchell H, Joseph C, Wedner J. 1998. Successful Techniques for Retention of Study Participants in an Inner-City Population. *Controlled Clinical Trials* 19, no. 6: 544-554.

33 US Department of Health, Education, and Welfare. 1975. A Study of the Effect of Remuneration Upon Response in the Health and Nutrition Examination Survey. *Vital Health Statistics: Series 2, Data Evaluation and Methods Research* no. 67. DHEW publication number: (HRA) 76-1341.

34 National Center for Health Statistics. National Health and Nutrition Examination Survey: NHANES I Data Files Documentation/Codebook, 1971-75 http://www.cdc.gov/nchs/about/major/nhanes/nhanesi.htm.

35 National Center for Health Statistics. 1981. Plan and Operation of the Second National Health and Nutrition Examination Survey 1976-80. *Programs and Collection Procedures* 1, no. 15. DHHS Publication No. (PHS) 81-1317.

36 Khare M, Mohadjer L, Ezzati-Rice T, and Waksberg J. 1994. An Evaluation of Nonresponse Bias in NHANES III (1988-1991). *Proceedings of the Section on Survey Research Methods of the American Statistical Association, Alexandria, VA: American Statistical Association.* 949-954.

37 Chromy J, Bowman K, Crump C, Packer L, and Penne M. 1999. Population Coverage in the National Household Survey on Drug Abuse. *Proceedings of the Section on Survey Research Methods of the American Statistical Association* 576-580.

38 http://www.samhsa.gov/oas/nhsda/methods.cfm

39 Judkins D, Shapiro G, Brick J, et al. 1999. 1997 NSAF Sample Design. *NSAF Methodology Reports. Washington, D.C.: Urban Institute.*

40 Brick M, Flores-Cervantes I, Cantor D. 199. 1997 NSAF Response Rates and Methods Evaluation. Report No. 8. *NSAF Methodology Reports.* Washington, D.C.: *Urban Institute.*

41 Lebowitz M, Knudson R, and Burrows B. 1975. Tucson Epidemiologic Study of Obstructive Lung Diseases. *American Journal of Epidemiology* 102, no. 2: pp. 137 – 152.

42 Mack S, Huggins V, Keathley D, Sundukchi M. 1998. Do Monetary Incentives Improve Response Rates in the Survey of Income and Program Participation? *Proceedings of the Section on Survey Research Methods of the American Statistical Association, Alexandria, VA: American Statistical Association.* 529-534.

43 Keeping JD, et al. 1989. A Prospective Longitudinal Study of Social Psychological and Obstetric Factors in Pregnancy: Response Rates and Demographic Characteristics of 8,556 Respondents. *British Journal of Obstetrics and Gynecology* 96 (March): 289-297.

44 Strauss W, Nishioka M, Reiches N, Ma J, Lehman J, Brown V, Ryan L, Spiegelman D, Fitzmaurice G, Loecke D, Harezalk J, Kalton G, Brock D, Choudhry H, Clickner R, Chu A. 2003. Development of Exposure Assessment Study Design for the National Children's Study. *Final Report, Task Order 19. Contract no. 68-D-99-011, submitted to USEPA, Office of Research and Development.*

45 Cox B, Massey J, O'Connor D. 2000. An Investigation of Response Rates in Random Digit Dialed (RDD) Telephone Surveys. *Personal Correspondence.*

46 Council of American Survey Research Organizations. 1982. On the Definition of Response Rates. *A special Report of the CASRO Task Force on Completion Rates. New York: CASRO*

47 Booth A, Johnson D. 1985. Tracking Respondents in a Telephone interview Panel Selected by Random Digit Dialing. *Sociological Methods and Research.* 14:53-64

48 Brick M, Collins M, Davies E, Chandler K. 1997. Feasibility of Conducting Follow-up Surveys in the National Household Education Survey. *U.S. Department of Education. National Center for Education Statistics, NCES 97-335. Washington, DC.*

49 Drew J, Choudhry G, Hunter L. 1988. Nonresponse Issues in Government Telephone Surveys. *In R.M. Groves, D.P. Biemer, L.E. Lyberg, J.P. Massey, W.L. Nicholls, and J. Waksberg (Eds.), Telephone Survey Methodology,* 233-246. New York: John Wiley and Sons.

50 Sharp L. 1984. Researchers and Respondents in the 1980's. *Public Opinion Quarterly*. Fall (48), 680-685. Presidential Remarks at AAPOR's 39th Conference.

51 Apodaca R, Lea S, Edwards B. 1998. The Effect of Longitudinal Burden on Survey Participation. *Proceedings of the Section on Survey Research Methods of the American Statistical Association, Alexandria, VA: American Statistical Association.* 906-910

52 Klerman J. 1992. Pitfalls of Panel Data: The Case of the SIPP Health Insurance Data. *The Rand Corporation.*

53 Singer E, Van Hoewyk J, Gebler N. 1999. The Effects of Incentives on Response Rates in Interviewer-Mediated Surveys. *Journal of Official Statistics* 15: 217-230.

54 Church A. 1993. Estimating the Effect of Incentives on Mail Survey Response Rates: A Meta Analysis. *Public Opinion Quarterly* 57:62-79

55 Duncan G, Kalton G. 1987. Issues of Design and Analysis of Surveys Across Time. *International Statistical Review.* 55:1:97-117

56 Capaldi D, Patterson G. 1987. An Approach to the Problem of Recruitment and Retention Rates for Longitudinal Research. *Behavioral Assessment.* Vol 9:169-177

57 Bender B, Ikle D, DuHamel T, Tinkelman D. 1997. Retention of Asthmatic Patients in a Longitudinal Clinical Trial. *Journal of Allergy and Clinical Immunology.* Vol 99. No. 2

58 Blumenthal D, Sung J, Coates R, Williams J, Liff J. 1995. Recruitment and Retention of Subjects for a Longitudinal Cancer Prevention Study in an Inner-City Black Community. *Health Services Research* 30:1 (April, Part II)

59 U.S. Census Bureau. 2003. Migration of the Young, Single, and College Educated: 1995 to 2000. *Census 2000 Special Reports.*

60 U.S. Census Bureau. 2001. Geographical Mobility Population Characteristics March 1999 to March 2000. Washington, DC.

61 Federal Committee on Statistical Methodology. 1985. Statistical Policy Working Paper 13 – Federal Longitudinal Surveys. www.fcsm.gov/working-papers/sw13.html.

61 Morrison T, Wahlgren D, Hovell M, Zakarian J, Burkham-Kreitner S, Hofstetter R, Slymen D, Keating K, Russos S, Jones J. 1996. Tracking and Follow-up of 16,915 Adolescents: Minimizing Attrition Bias. *Controlled Clinical Trials.* 18:383-396.

62 Graham J, Donaldson S. 1993. Evaluating interventions with Differential Attrition: The Importance of Nonresponse Mechanisms and Use of Follow-up Data. *Journal of Applied Psychology.* 78(1): 119-128.

63 Burgess R. 1989. Major Issues and Implications of Tracing Survey Respondents. *In D. Kasprzyk, G. Duncan, G. Kalton, and M.P. Singh (Eds.). Panel Surveys.* 52-74. New York: John Wiley and Sons.

64 Cox C, Mussolino M, Rothwell S, et al. 1997. Plan and Operation of the NHANES I Epidemiologic Follow-up Study 1992. National Center for Health Statistics. *Vital Health Stat* 1(35).

65 Goldstein H. 1979. The Design and Analysis of Longitudinal Studies: Their Role in the Measurement of Change. *Academic Press.*

66 Hahn L, Sprafka J, Burke G, Jacobs D. 1990. Comparison of Two Procedures for Tracing Participants in an Epidemiologic Cohort Study. *Epidemiology*. 1:157-160

67 Bindman A, Grumbach K, Keane D, et. al. 1993. Collecting Data to Evaluate the Effect of Health Policies on Vulnerable Populations. *Participant Med.* 25:114-119.

68 McDonald P, Evans A, Baxter J, Gray E. 2000. The Negotiating the Life Course Survey Experience. *Negotiating the Life Course Discussion Paper Series Discussion Paper DP-001*.

69 Hogan H. 1983. The Forward Trace Study: Its Purpose and Design. *Proceedings of the Section on Survey Research Methods of the American Statistical Association, Alexandria, VA: American Statistical Association.* 168-172.

70 Mulry M, Dajani A. 1989. The Forward Trace Study. *Proceedings of the Section on Survey Research Methods of the American Statistical Association, Alexandria, VA: American Statistical Association.* 675-680.

71 Turner S, Le Souef P. 2003. Is Patient Dropout From a Longitudinal Study of Lung Function Predictable and Reversible? *Pediatric Pulmonology.* 35:29-33

72 www.sipp.census.gov/sipp/types_non.html

73 McGuigan K, Ellickson P, Hays R, Bell R. 1995. Tracking, Weighting, and Sample Selection Modeling to Correct for Attrition. *Proceedings of the Section on Survey Research Methods of the American Statistical Association, Alexandria, VA: American Statistical Association.* 402-407.

74 Kalton G. 1983. Compensating for Missing Survey Data. *Survey Research Center, University of Michigan,* Ann Arbor.

75 Heckman J. 1979. Sample Selection Bias as a Specification Error. *Econometrica.* 47(1):153-161.

76 National Center for Health Statistics. Bachrach C, Horn M, Mosher W, Shumizu I. 1985. National Survey of Family Growth, Cycle III, Sample Design, Weighting, and Variance Estimation. *Vital and Health Statistics.* Series 2. No. 98. DHHS Pub. No. (PHS) 85-1372. Public Health Service. Washington. U.S. Government Printing Office.

77 Kalton G. 1986. Handling Wave Nonresponse in Panel Surveys. *Journal of Official Statistics.* 2:303-314

78 http://dsp-psd.communication.gc.ca/Collection/RH63-1-561-01-03E.pdf

79 http://www.hrdc-drhc.gc.ca/sp-ps/arb-dgra/nlscy-elnej/home.shtml

80 http://www.wws.princeton.edu/~kling/surveys/ECLS.htm

81 http://aspe.os.dhhs.gov/datacncl/datadir/cdc3.htm#nhanes1

82 www.ansoc.uq.edu.au

APPENDIX G-A

INFORMATION ON RECRUITMENT AND RETENTION FROM A PREVIOUS STUDY

Strauss et. al. (44)

Table A-1. Long-Term Response Rates (Taken from Strauss et. al., [44])

Study Number	S1	S2	S2	S3	S4	S5	S6	S7[a]	S10[b]	S12	S23-m[c]	S23-k[c]	S47[d]
Study	MUSP	CHDS		BBC-1946	MSRC	DMHDS	BBC-1958	DBC	CPP	SLPS	ALSPAC		ECLS-K
		New Zealand		England, Wales, and Scotland			England, Wales, and Scotland		USA, many States		UK, Southwest		
Locale	Australia	New Zealand Cohort	Original Cohort		Germany	New Zealand		Dutch		USA	Mothers	Children	USA
Under 1 month	86.3	100.0	100.0						95.2	82.0		90.4	
At 1-6 Months	78.3	97.4	97.4		100.0				83.7		87.7		
At 6-12 months		96.9	93.3						79.2	82.0	85.2	84.6	
At 2 years		96.6	91.4	91.2	97.8					82.0	80.8	81.3	
At 3 years		96.2	90.4			100.0					77.5	80.6	
At 4 years		96.2	89.1	91.4	96.7					82.0	77.6	80.9	
At 5 years		96.1	88.8			95.6							88.3
At 6 years		95.8	88.2	89.5									73.4
At 7 years		95.2	87.5	87.1		92.0		100.0	75.5	82.0			
At 8 years		94.2	86.3	86.2	96.1								
At 9 years		93.2	85.3	81.3		92.1		81.0					
At 10 years		92.4	84.3	79.3									
At 11 years		92.0	82.8	83.2		89.2		83.0					
At 12 years			81.6										
At 13 years			81.6	80.2		82.0		85.0					
At 14 years			81.6							82.0			
At 15 years		84.5	81.6	83.1		94.1		68.5					
At 16 years			81.6										
At 17 years			81.6										
At 18 years			81.6			97.2							
At 19 years			76.2	69.2									
At 20 years			76.2	75.8									
At 21 years			76.2			92.7							
At 22 years				75.5									
At 23 years				58.8			76.0		74.7				
At 25 years				64.3									
At 26 years				72.9									
At 31 years				64.9									
At 33 years							69.0						
At 36 years				64.6									
At 43 years				63.4									

a. DBC (S7) covers selected children from 4 to 18 years old for 5 different waves. The response rates are estimated at 2-year interval waves instead of the children's age.
b. CPP (S10) the response rates between birth to 1-year included Black and White mothers, only single-births. At 7 years, the response rates included all deliveries. At 23 years, the response rate only involved a sub-sample of approximately 1,000.
c. ALSPAC –mother (S23-m) and ALSPAC-kid (S23-k) sent out questionnaires to less than the number of eligible mothers/kids. The average response rates are adapted from the Web-pages.
d. ECLS-K (S47) – unweighted completion rate for child assessment at 5-years old and 6-years old.